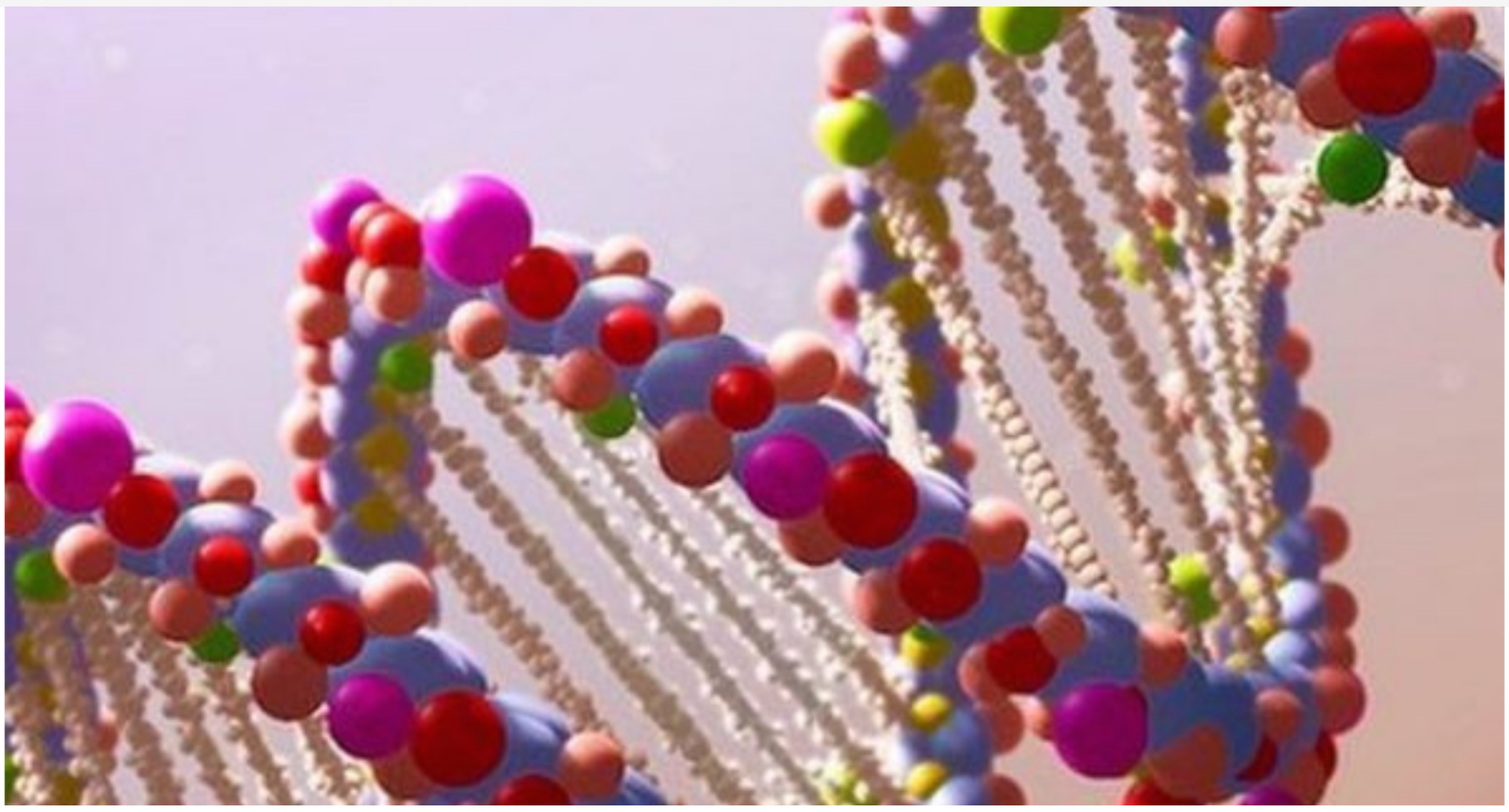
Fun and Fallacy in Consumer Genetics Marketing



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In a rare moment of TV surfing at the weekend, I was transfixed by a lengthy advert that appeared on the Sky News channel for 23andMe, the direct-to-consumer genetic testing company, promoting its home testing kit, available for only £125, shipping included. Hobbled by the US FDA in 2013 for infringing medical device regulations by suggesting it could diagnose and predict health conditions, 23andMe launched in the UK in December under the softer guise of infotainment. (1) It offers the ordinary citizen the chance to have their genetic profile and family history analysed for a modest cost, like a sort of fortune teller's crystal ball that looks to the past, present and future.

The societal and ethical implications of such data uses are huge. Genetic data isn't exclusively the data-giver's, it also represents their relatives and can generate predictions about them, not all of which they may wish to be known. This is made stronger by the convergence with family histories (phenotypes) whose ownership is also debatable. Critically the ownership of the enriched data assets these companies will eventually hold is unclear and their potential value for commercial research is incalculable. 23andMe promises that it won't share people's data with insurance companies or 'other interested parties', without explicit consent, but it is free to use it for the purposes of its own medical research (2) and the CEO was recently forced to defend its partnerships with major pharmaceutical companies. (3) It comes as no surprise that data-hungry Google is one of 23andMe's backers, despite the recent uncoupling of their respective founders. (4)

This raises important questions, not least about who is really the customer in this multi-layered business model - is it the citizen paying for the test or external companies paying for their data, and who is gaining the most value from the relationship? It also raises questions about trust and the extent to which citizens purchasing these services truly understand what is being asked of them when they consent to uses of their data for 'medical research'. Similar questions have arisen for related initiatives in the public sector, with the UK Department of Health recently coming under fire for its handling of the consent information given to participants in the 100,000 Genomes Project. (5)

As the digital dots join and companies converge the potential for our personal information, and arguably our identities, to be siphoned off is just as great as the potential for innovation to yield medical advances. Getting the balance right will require honesty and transparency. The marketing of 23andMe as an entertaining curiosity belies its true power and is a cause for concern.

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2. Google's Sergey Brin and 23andMe's Anne Wokcicki legally divorced. Laura Lorenzetti, Fortune, June 24th, 2015 http://fortune.com/2015/06/24/google-sergey-brin-anne-wojcicki-divorce/
3. Despite regulatory troubles, DNA testing firm 23andMe raises more money . Kia Kokalitcheva, Fortune Magazine, July 2nd, 2015 http://fortune.com/2015/07/02/23andme-genetic-testing-funding/
4. 23andMe CEO defends practice of sharing genetic info with pharma companies. Lydia Ramsey. Business Insider UK. July 7th, 2015 http://uk.businessinsider.com/23andme-anne-wojcicki-marketplace-interview-2015-7?r=US
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